

Experiencing Guillain Barré: a mother and daughter perspective

One morning last summer, I first felt slight pins and needles in the palms of my hands and the soles of my feet, I didn't take much notice, then when I bent over to tie my shoe laces my back ached and I felt like I couldn't get back up. The next day I felt like I was walking through water, I found it hard going up and down stairs, I felt lethargic and I was really thirsty; my mum said that it could be growing pains. A week later, I went to Accident and Emergency (A&E) where they said it could be Guillain Barré syndrome (GBS). I was sent up to a children's ward and two doctors explained what GBS was and said that it could get worse but I will recover – I didn't really realise how bad I could get and just thought I'd be out by the end of the week. They decided to give me immunoglobulin to slow the virus and to stop it from spreading. I had 1 hour observations for the rest of that day including at night which was annoying, so I didn't sleep much but I was really restless anyway. The next day I got worse. My face muscles went slack and it felt like my face was drooping, even my eye lids were weak, they felt really heavy and I couldn't close them properly; my lips were slightly swollen and I couldn't close those properly either and so found it hard to eat. To get off my bed I had to slide my legs off one at a time mainly using my hands to lift them, I had to use my mum to get up and then found that I couldn't walk so I had to use a wheelchair. I had another dose of immunoglobulin 10 days later. By then I don't think I could use my legs at all and my arms were getting weaker; my peak flow had dropped from 250 to 150. During this time I just wanted my mum to deal with the doctors and all the questions asked of me, I just wanted to go through it and be done with it. At times, mainly at night, I was in pain and it felt like I just needed to stretch all the time. It wore me out because I couldn't sleep and I was always very thirsty. After a while this would upset me, I felt more angry then upset, I wanted the doctors to tell me what to do, how to make everything better, just to make it pass quickly. Every time I needed the loo or anything I had to call the nurse and if it was a new nurse I had to tell them how they were to help me – I found it so tedious when they couldn't do it correctly. I looked forward to visitors because I was not alone, and they were someone new to talk to about something different and not about me. Sometimes I found the visitors annoying

when they would either just sit there in silence not saying anything but occasionally glance at my legs as if they were trying to see the virus in me, or when they would constantly ask me questions. It annoyed me because I had the same-ish questions from the doctors everyday and my answers were always the same. The slightest thing, like having a bad visitor or nurse, could decide whether I had a good or a bad day. Another thing that didn't help was the nutritional value of spaghetti hoops, as that was the only thing that tasted ok and that I could eat from the menu. The food was disgusting, even the doctors and the lunch ladies admitted that it was gross! I had practically memorised the menu off by heart as it was the same every week. My mum had to go out everyday to either buy food, make it or tell my dad to attempt something. I was very disappointed because for my illness nutrition was very important. It was the only medicine. How were any of the children in the ward supposed to recover successfully if they didn't have any real food? The first time I went out of the hospital was probably around the end of the 2nd month. I was in a wheelchair and my physio decided to take me out to show mum how to control the chair (up and down kerbs, etc). We had a bit of difficulty at the beginning because the kerb outside the hospital is steep and there was no way of crossing the road unless you tilt the chair (of course with me in it) at a 45 degree angle down the kerb, turn me around, cross the road then turn me around again and tilt me forwards (this was when I thought I was about to fall out or fall forward which I had done before and it was the most terrifying experience that I had ever had) to get back onto the pavement. Being just outside the hospital was OK because there were other disabled people too sometimes, but as we moved further along the road more people could see me. Everything was different because I could only look at things at my eye level which was a lot lower because I was sitting down. This also meant that if people were to look at me they would have to look down to see me or just not look at all. Sometimes I would see people I knew but it would be different, they would crouch down to talk to me or if they were talking to my mum I felt uncomfortable because I couldn't see them, I didn't know what was going on. I also felt odd because you can't see who is pushing you so it feels like you're alone. Because the chair was

obviously a lot wider than me standing up, people moved out of the way more, and seemed to be further away from me. When we got back to hospital and my physio had left I started crying. I thought going outside would be nice, but I hated it. I felt like I was living in someone else's body. I didn't want to go out again anytime soon – I was too scared. I soon got used to it, but I didn't need to because I was on the path of recovery and soon I was using a walker when I went home and was able to transfer in and out of a car, and then crutches later. Now I can walk unaided with just a few minor problems which will go in time.

PARENT/CARER'S VIEW

As a parent, my first feeling was just like my daughter's: we would get to the hospital, get some medication and go home to rest and recover. When they started taking extra blood samples for more tests and saying that we needed to be admitted immediately, fear began to settle in. We had never heard of GBS or what such an illness entails. Though I had a thousand questions to ask, my immediate thought and request was for the doctors to assess her and treat her. Every moment we waited she got worse. They said the illness could take several different paths and this would dictate the intensity and severity of it. How long it took to peak and then stop would then also have an effect on her and on recovery. To watch a very active teenager lose mobility so quickly was horrific. Despite being very close to my daughter, I have little understanding of the sheer terror and fright she must have felt. I feel ashamed that I could not relate to her feelings and could only comfort her with words and hugs, but soon we could not even hug and my words were not sounding strong. At this point the doctors told me that I had to project a very positive image and keep her calm and optimistic. Now, a year in I can say that they were right, this illness does pass, though it seems unbelievable when it first happens. My anxiety was there, I needed solid proof, but who can do that but the one above? I made demands on the medical staff for reassurances and more facts. I felt that things would feel better the more I knew. However, not all facts are easy to digest, so all I can say is that a good support team is essential. As much as the doctors comforted and reassured us, they also had other patients to see. As this is a rare illness, we were very lucky that one

of the nurses had dealt with such a case before, and continual advice from her was priceless. She helped us to pass the day; she was able to advise me how to help with all the basics like changing clothes, toileting and eating. Our time of greatest trauma and need was when we came in to A&E. It is particularly important that the diagnosis is made correctly and immediate action is taken with a care team set up of experienced staff who are able to deal with the crisis and also be supportive. I have and I continue to thank God for the blessed support team in A&E, who were followed up with an equally excellent team of staff in the ward. I wanted the relevant staff to do what they are experienced to do and at the same time I continually sought reassurance and emotional support. It was a lot of "I want!" and I realise now that I had become my daughter's spokesperson. Maybe because she was so young, or so scared, she wanted me to deal with all the daily questions and details. She just wanted to be told what to do and that she would get better. She wanted no more facts about the illness and I now realise that if I told her all the details I had been given, it upset her a lot. At times she was frightened, at times she just

cried, at times she was very angry, it seemed endless. I must give praise to her because in public she was always very brave and only got upset in private. Such a young child to be so much in control! Before we went home, the most important thing for us was that there should be continuity of care. We were to have a community support team but this needed setting up. She was doing so well and so we wanted to continue this at home, but it was a battle with the authorities to set up and maintain all the systems until complete recovery. It should not be like this! Sometimes (or should I be honest and say most of the time) it was lack of funds that hindered any plans and finding ways round this was the hardest thing. It is not fair on the medical professions to battle with red tape when their services are so needed concerning the real issues of their normal working day. The last stage (I write this one year on) is what I call the aftermath. My daughter is about 90% back to herself, though sometimes she still get aches and pains and fatigue. Now she is physically stronger, the reality of what has happened is taking its toll. She is crying and grieving at the time lost and also angry at why it happened to her. These are healthy

emotions of course and we are dealing with them. I had to resort to private finance in the period after coming home as the only way to maintain my daughter's rehabilitation because there was limited support from the NHS due to lack of funds! As already mentioned, continuity is very important at this final stage. It is very sad that despite several attempts from the consultants they could not find a rehabilitation centre that would accept her. At this stage you wonder where all the contributions you have paid have gone and about the true state of the NHS. We have survived with emotional scars to show, but we hope that future patients can receive all the relevant care and their needs be properly acknowledged.

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Taruna Mistry and her daughter

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